



Statement of the National Alliance on Mental Illness (NAMI)

SUBMITTED TO
HOUSE SUBCOMMITTEE ON HUMAN RESOURCES OF THE
COMMITTEE ON WAYS AND MEANS
WASHINGTON, D.C.

Chairman Davis, Ranking Member Doggett, and Members of the Subcommittee –

The National Alliance on Mental Illness (NAMI) greatly appreciates this opportunity to submit written testimony related to the October 27, 2011 hearing on Supplemental Security Income (SSI) benefits for children.

INTRODUCTION

NAMI is the nation's largest grassroots family and consumer organization dedicated to improving the lives of children, adults and families affected by mental illness. Through NAMI's 1,100 chapters and affiliates in all 50 states NAMI supports education, outreach, advocacy and research on behalf of persons with mental health conditions.

NAMI is also a member of the SSI Coalition for Children and Families, a network of more than 80 family, consumer, professional and advocacy organizations dedicated to advocating on behalf of families caring for children and youth with severe mental and physical disabilities.

The SSI program was established to provide income supports for low income families of children and youth with severe disabilities. Families rely on this funding to help support the needs of their children. NAMI routinely receives requests for assistance from families who are struggling with the hardship that comes with raising a child with a serious mental illness.

Many of these families share the extreme challenges they face in trying to keep their jobs while frequently being called away to come and get their child from daycare programs, schools and other community programs. Most schools and community programs struggle with effectively addressing the needs of children with severe mental illness. Many parents are forced to leave their jobs because of the demanding day-to-day needs of their child, their child's challenges in participating in structured programs, their child's challenges in acquiring basic life skills (like following directions, getting along

with others, controlling and regulating their emotions and more), the need to take their child to therapeutic appointments and more.

ADVANCES IN UNDERSTANDING MENTAL ILLNESS IN CHILDREN

Serious mental illnesses among children and youth are as real and disabling as other physical illnesses such as epilepsy and juvenile diabetes. The National Institute of Mental Health (NIMH) observes that half of all psychiatric illnesses begin by age 14 and calls them “the chronic conditions of the young.” The World Health Organization has identified five of the top ten causes of disability and lost productivity in the world as being caused by psychiatric disorders.

NIMH has invested in multiple research studies that show that the onset of mental illness, including serious mental illnesses that cause severe disability, is most often in early childhood and adolescenceⁱ. We have learned a great deal over the past decade about how to identify mental illnesses in children and youth. Understandably, this has led to an increase in the number of children who have been diagnosed with these conditions.

Psychiatric impairments can affect a child’s learning, growth, socialization, and development as profoundly as it affects an adult’s ability to work. For example, adolescents with psychiatric disabilities have more than double the rate of dropout from high school than the general population. In fact, according to the United States Department of Education, children in the emotional disturbance (ED) category of The Individuals with Disabilities Education Act (IDEA), which includes children with serious mental health conditions, have the highest drop-out rate of any disability group receiving special education services. This is true for children whether or not they are enrolled in the SSI program. This is not a reflection of how well the SSI program works for these children or whether SSI creates disincentives for children to remain in school. Rather, it reflects the reality that our nation’s schools often struggle with how to effectively address the academic and functional needs of students with mental health conditions.

We know this firsthand because NAMI provides an in-service education program for school professionals in nineteen (19) states across the country. We have learned a great deal from working directly with schools and school staff. Many teachers, school administrators and other school staff have candidly shared with us that they struggle with effectively meeting the needs of students with mental health conditions and in the ED category of IDEA. They acknowledge their concern that this impacts the high school drop-out rates of these students. So to attribute the high drop-out rates to the SSI program is contrary to what is actually happening in schools around the country and is a gross oversimplification of a far more complex issue. There are many factors impacting whether students with mental health conditions stay in school and succeed. These include the challenges in accessing effective mental health services because of a critical shortage of child psychiatrists, the lack of training for school professionals to help them understand the effective programs and accommodations that help students with mental illness succeed in school, the different learning styles that many of these students have that are often difficult to address in large schools and classrooms and more.

It is important to recognize that only children suffering with severe mental and/or physical disabilities are eligible for SSI. The review process looks at a child's functioning and not solely at the diagnosis, which is important because children with conditions like Attention Deficit Hyperactivity Disorder (ADHD) may experience very different levels of functioning. Some children with ADHD have very low functioning and struggle with attending and participating in school, in following even basic directions, become involved in substance use and abuse and become involved in the juvenile justice system. Whereas others may have a milder form of ADHD and would not qualify for SSI. This is also true for children with Autism.

Also, many children with a primary diagnosis of ADHD also have co-occurring disorders, including bipolar disorder, depression, anxiety, learning disabilities and autism spectrum disorders.ⁱⁱ When children have multiple co-occurring disorders, their function is often extremely impaired and they often struggle in the multiple domains of their lives, including in school, at home and in the community. In these cases, low income families need the financial support provided by the SSI program to help provide food, clothing and housing for the child, which becomes all the more important when parents cannot work because they must remain close to home for the child.

Serious mental illness in children often responds well to effective programs, services and treatment. The SSI program is a life line for parents, allowing them to take their children to therapeutic appointments and to see specialists who help children acquire the basic life skills they need to remain at home with their families and out of far more costly institutional settings.

Psychiatric medications, when properly prescribed and monitored, are an important component of psychiatric treatment and have proven effective in reducing disability and fostering recovery among youth with mental illnesses. Health conditions are exacerbated by the consequences of poverty, so getting stable resources to low-income children with mental illnesses is critically important.

Proposals to limit eligibility and reduce benefits would be harmful to these struggling families. Without the necessary services and supports afforded by SSI, these children's functioning would likely deteriorate, and any projected "savings" realized by cuts would quickly be exceeded by escalating costs incurred by child welfare, public safety, juvenile justice, and publicly-funded institutional care.

NAMI SUPPORTS AN IOM STUDY

NAMI joins Representative Richard Neal (D-MA) and Social Security Administration (SSA) Commissioner Michael Astrue in calling for an IOM study to examine the children's SSI program. Given the importance and value of this program to children with severe mental and physical disabilities, expert guidance and a thorough study of the program is needed before any drastic measures are taken to change the program. Convening a body of experts to conduct a thorough review of SSI is the only way that we will understand what is working well and has proven cost effective in the program and how to ensure the program's ongoing integrity. Future policy decisions

about SSI should be made based on facts and evidence rather than unsubstantiated and anecdotal claims.

NAMI SUPPORTS IMPROVEMENTS TO SSI

Before turning to actions that can be taken to improve the SSI program for children, it is important to recognize the safeguards that already exist in the administration of the SSI program. SSI has strict eligibility criteria and standards that result in more than half of the SSI applications being denied every year for children with mental health conditions. Decisions about whether a child qualifies for SSI are only made after a record review and input from multiple sources, including health care providers, school professionals and other adults working with the child. The review process involves determining a child's level of functioning in multiple settings, including home, school and other community settings.

The continuing review process is designed to be rigorous. The SSA is required to conduct Continuing Disability Reviews (CDRs) every three years for conditions that might improve, at age 18 to determine if applicants meet adult SSI criteria and as part of Performance Accountability Reviews. These reviews are absolutely essential to ensuring the integrity of the program. According to the preliminary report released by the U.S. Government Accountability Office (GAO)ⁱⁱⁱ, SSA has struggled to meet the CDR requirements because of limited federal funding. NAMI applauds the recent enactment of the Budget Control Act of 2011 which authorizes increased funding for SSA to conduct CDRs and redeterminations.

NAMI supports improvements to the program to help ensure ongoing program integrity and that children with severe mental illness are receiving the support they need to stay in school, receive therapeutic care to help them develop basic life skills and to work toward leading independent and productive adult lives.

Despite the safeguards that exist in the SSI program, there are certainly areas that can be improved. NAMI calls on Congress to take the following steps to ensure the ongoing integrity of the SSI program for children with severe mental illness:

- Continue to provide adequate funding to allow the SSA to meet their continuing disability review requirements to help ensure the ongoing integrity of the SSI program for children;
- Authorize and fund an IOM study to allow a body of experts to conduct an in-depth review of the program;
- Strengthen the interagency collaboration across federal agencies, including the U.S. Department of Health and Human Services, the U.S. Department of Labor, SSA, the U.S. Department of Education, and the Center for Medicare and Medicaid Services -- to encourage the development of effective cross-agency educational, vocational rehabilitation and supported employment programs for youth and young adults living with severe mental illness. This collaboration should focus on improving educational outcomes, increasing the availability of

supported employment programs and raising awareness about SSI work incentive and other programs that encourage SSI recipients to work.

NAMI urges the committee to avoid drastic changes to the SSI program for children that could ultimately harm children and families. NAMI opposes any changes that would turn the SSI program for children into a state administered program through either a block grant or by adding it to the existing TANF program. This would lead to the elimination of national standards, would not allow vitally important oversight of the program and would place a high administrative cost burden onto states. The more prudent approach is to take an in-depth look at what works in the SSI program and to make any necessary adjustments that will help to improve the program and the young lives that it was originally created to support.

ⁱ NIMH Director's Blog, April 2010, accessed at www.nimh.nih.gov.

ⁱⁱ NIMH Publication: "What Conditions can coexist with ADHD." Accessed at www.nimh.nih.gov.

ⁱⁱⁱ Statement of Daniel Bertoni, Director, Education, Workforce and Income Security, U.S. Government Accountability Office. Submitted on October 27, 2011. GAO-12-196T.